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HEALTH CAMPAIGN PLAN: INCREASING FAMILIAL CONVERSATIONS ABOUT
ORGAN DONATION

by

Olivia Vibert

A Thesis in Partial Fulfillment of the Requirements

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ABSTRACT

Organ transplantation is a medical practice dates back to the 1920s and has led to tens of thousands of lives being saved. Currently, there is a massive shortage of organs suitable for donation in the United States with more than 114,000 men, women, and children on the organ waiting list, with less than 20,000 registered donors (Department of Health and Human Services, 2019). This paper covers the history of organ donation, where the issue of the lack of organs currently stands, and the role communication plays in carrying out one's choice to donate. Understanding these factors has led to a health campaign plan based on a template created by George Washington University. The goal of the plan is to aid in increasing formal conversation between young adults and their next of kin about organ donation choices and the decision making process, so that the next of kin will be more likely to make the choice consistent with the young adults' decisions concerning their organs

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INTRODUCTION

According to the Department of Health and Human Services (2019) as of January 2019, more than 114,000 people were waiting for an organ transplant in the United States and 20 people per day, on average, die while waiting. Organ transplantation experimentation began in the 1920s and has led to massive medical breakthroughs that have saved the lives of tens of thousands. There is the need to increase the donation rate. Direct and open communication with family about one's desire to donate his/her organs could help increase the number of donations. In order to understand the current state of organ donation, it is important to review the history of the medical procedures up to the present day, as well as the legal standards and institutions involved. Relevant communication theories and literature guided the development of an integrated plan focused on familial communication about organ donation.

HISTORY OF ORGAN DONATION

Early History

Organ donation has been used as a successful medical technique in saving the lives of tens of thousands of patients. The history of organ donation is one that is filled with trial and error and scientific exploration into the human body (see Table 1). Howard Cornell, and Cochran (2012) point out that in the early twentieth century skin and corneas had been successfully transplanted as the first step towards modern transplantation. In the 1920s, surgeons began experimenting with transplantation of parts of animal anatomy into humans as a solution for several different medical problems. The first human-to-human kidney transplantation was performed by the Russian surgeon Dr. Yu Yu Voronoy in 1936 (Barker & Markmann, 2013; Howard et al., 2012). The recipient patient, who was blood type O, had acute renal failure as a result of mercury poisoning, and the donor had blood type B and had been dead for six hours at the time of the procedure (Howard et al., 2012). Blood type differences and the time of death were later cited as reasons the kidney never functioned, which resulted in the death of the patient two days after the procedure (Howard et al., 2012). By the 1940s doctors had perfected the procedure for cornea transplantation allowing for the Manhattan Eye, Ear and Throat Hospital to create the first eye bank in 1944 (Keller, 2003). It is interesting to review these works to understand the medical experimentation of organ donation specifically around kidney donation, as they play a vital role into the development of the organ donation as a whole.

In 1953, in France, the first living donor kidney transplantation was performed with a mother donating to her son. This kidney functioned for three weeks before the patient eventually died of rejection (Howard et al., 2012). The following year, the first

successful kidney transplantation was done between identical twin brothers Ronald and Richard Herrick, by Dr. Joseph Murray at the Peter Bent Brigham Hospital in Boston (Barker & Markmann, 2013; Howard et al., 2012; Jonsen, 2012; Keller, 2003). Richard, the recipient, survived for another eight years, and the donor, Ronald, lived for another 56 years. Its success had been largely attributed to the fact that immunosuppressive drugs were not needed because the donor and recipient were identical twins (Barker & Markmann, 2013; Howard et al., 2012; Keller, 2003). Until the development of immunosuppressants, transplantation would not be considered a viable option for renal failure, but the lack of other treatments for the illness was used as justification for continued experimentation (Barker & Markmann, 2013). According to Keller (2003), Dr. Peter Medawar identified that the rejection was occurring because the bodies of the recipients were recognizing the foreign body and creating antibodies to reject the antigens, through this discovery tissue typing and immunological identities proceeded to help combat the potential for rejection. Dr. Murray also performed the first successful kidney transplantation with a deceased donor in 1962 (Howard et al., 2012). By this time there were several transplantation centers established throughout the United States and Europe.

In the 1960s, several other surgeons successfully performed transplantations of other organs, including a lung transplantation (1962); liver transplantation (1963); and a pancreas transplantation (1966). Dr. Christian Barnard performed the first successful heart transplant in 1967 (Howard et al., 2012). The first documented transplantation of a kidney using a brain-dead patient was in 1963 by Guy Alexandre, who at Saint Pierre Hospital in Louvain, Belgium transplanted the kidneys of a patient who had suffered a

head injury that resulted in a coma (Howard et al., 2012). This procedure started the movement towards the expanded criteria for potential donors.

Introduction of Brain Death

In the beginning of organ donation research, only deceased donors were considered viable candidates, but as research continued, the medical community realized that for kidneys, live donors could be used as well. A living donor is a donor who is alive at the beginning of the donation and is expected to be alive at the end of the donation procedure, whereas a deceased donor is deceased at the start of the procedure (Howard et al, 2012; Keller, 2003). In the early development of transplantation, the dead donor rule was implemented, dictating that “all donors who are expected to be dead at the completed of organ donation must be dead before organ recovery is undertaken” (Howard et al., 2012; Keller, 2003). In several documented instances however, this rule was violated for the sake of recovering the organs. Such was the case with recovery with patients who had undergone open-heart surgery but would be unable to recover once taken off bypass, or in the case with patients who had sustained severe brain injury from trauma whose condition was maintained by a mechanical ventilation system (Howard et al., 2012). Patients could not be pronounced brain dead at this point, because no such laws or legal precedence had been created (Howard et al., 2012). Previously, when surgeons used patients who were on mechanical ventilators, the surgeons would bring the patient to the operating room, shut off the machines, and wait for the patient’s heart to stop before recovery began. Early on, surgeons acknowledged that organs from living donors functioned better than those recovered from deceased donors whose hearts had stopped

beating (Howard et al., 2012; Keller, 2003). At this point however, the acknowledged brain death had no legal standing under the legal definition of death. In 1963 Dr. Alexandre performed the first documented kidney donation with a brain dead donor, he then went on to perform the surgery on eight subsequent patients and reported the results to the Chemical Industry in Basel (CIBA) Symposium in London in 1966. Alexandre presented his stance on the ethical implications of brain death, as well as formal clinical criteria for brain death, a proposal that was widely rejected by the medical community (Howard et al., 2012).

In the United States, in the 1965 Medicare/Medicaid Laws titles XVIII and XIX of the Social Security Act, there was a section which permitted removal of organs from heart-beating patients, and brain-dead donors as long as the closest relatives had given permission for donation, which in turn allowed Christian Barnard to legally perform the first heart transplant in 1967 (Howard et al., 2012). The publicity that resulted from his historic transplantation forced the medical community to begin to rethink the idea of brain-dead donors, and donation from brain-dead donors became invaluable to medical advancement (Howard et al., 2012).

In 1968, the Ad Hoc committee of Harvard Medical School published a formal report which defined brain death as a “total irreversible cessations of brain function, including the brain stem” (Barker & Markmann, 2013; Howard et al., 2012; Jonsen, 2012; Keller, 2003). In 1970, Kansas was the first state to adopt a brain death statute, and Finland was the first nation to accept brain death nationwide in 1972. In 1975, the American Bar Association established brain death as a legal concept in addition to be a medical concept (Howard et al., 2012). In 1980, the President’s Commission for the

Study of Ethical Problems in Medicine and Biomedical and Behavioral Research drafted the United States Uniform Determination of Death Act, which would allow brain death to become a legal standard. The act was approved in 1981 and defined death as “(1) irreversible cessation of circulator and respiratory function or (2) cessation of all function of the entire brain, including the brain stem” (Howard et al., 2012; Jonsen, 2012). This definition allowed for the harvesting of organs from individuals who were being kept alive through artificial means but were considered dead through the brain stem criteria (Jonsen, 2012). This definition of death was then published in *Guidelines for Determination of Death* and is in effect across all 50 states. The state laws that allow for donation are not uniform across the nation, and with different variables, including how many physicians are required to pronounce brain death, and timing of declarations, among others. Prevalent concerns still surround declarations of brain death, such as it being an unproven way of declaring someone dead, whether or not the brain is entirely dead, or whether or not a clinical diagnosis is adequate (Howard et al., 2012). Taking these findings into consideration it is easy to understand how the United States developed into a opt-in society because of the skepticism surrounding brain death despite the medical authorities findings. Currently the two types of donors are living donors and cadaveric donors, the latter being the most common source for transplants (Kastenbaum, 2016). Cadaveric donors can either be patients who have been declared brain dead, or Donation after Cardiac Death (DCD), which is more frequently used when the family members have agreed to end life-support efforts and the organs are removed within minutes of official cardiac death (Kastenbaum, 2016). With the expanded definition of

death, donation became an increasingly viable option for treatment which led to a need for a system of donation.

Development of Organ Donation Networks

In 1967 Paul Teraski established the first organ sharing organization in Los Angeles, with Boston Interhospital Organ Bank following in 1968 (Barker & Markmann, 2013). It is stated in the article *OPO History* from Association of Organ Procurement Center (2019) that during the early years of organ transplantation, everything was kept local. Transplant centers recovered the organs they needed for transplantation either at their own facility or through facilities where they had a geographic or personal connection with through the doctors. Through medical advancements, such as immunosuppressant drugs, transplantation became a reality for far more people and a more centralized network of sharing was needed (“OPO History”, 2019). From there, OPOs developed regionally within states and across state lines, to serve as the vital connection point between transplant center and donor hospitals (Howard et al., 2012). Dr. Richard Howard (2012) cites two major advances that lead to more cooperative efforts between transplant centers to exchange organs on a wider basis; the first being medical advances within preservation techniques and improved methods of tissue typing to match organs with potential recipients. Improved preservation techniques made transplanting between distant areas more feasible and improved methods of tissue typing allowed for donors to be matched with recipients which would reduce the risk of rejection drastically (Howard et al., 2012). In the late 1960s consolidation efforts of the OPOs began to create an improved system of communication between multiple transplantation centers, as

transplants increased exponentially. It is interesting to review these works to understand how organ transplant centers developed into the complex system that exists to serve the needs today. In 1977, the United Network for Organ Sharing (UNOS) was created and it eventually became a national network that is still used today (Barker & Markmann, 2013; Howard et al., 2012; Keller, 2003). UNOS is a nonprofit, charitable organization that states its mission as “to advance organ availability and transplantation by writing and supporting its communities for the benefit of patients through education, technology, and policy development” (Keller, 2003). The UNOS computer system began as a 24-hour alert system and answering machine developed and located at the University of Pittsburgh Medical Center, which served transplant centers east of the Mississippi River. A similar system based in California, was developed for centers west of the Mississippi (Howard et al., 2012). In 1984, with the passage of National Organ Transplant Act, the Organ Procurement and Transplant Network (OPTN) was established, mandating that all transplant candidates be on a national transplant waiting list and that all organs must be shared through the OPTN (Barker & Markmann, 2013; Jonsen, 2012; “OPO History”, 2019). In addition, this act enabled a task force to investigate the social, ethical and economic aspects of organ donation on a national level (Jonsen, 2012). According to Jonsen (2012), this task force affirmed two key principles that have shaped the American Transplant Ethos; firstly, that no financial compensation beyond medical costs should be given for donations and secondly that organs cannot be harvested from dead donors without permissions (Jonsen, 2012). With this act, regional organ sharing was ended, and it officially became nationally regulated.

As pressure increased to share organs within defined geographic areas and the high reluctance of hospitals to pay for the cost of organ procurement, organ banks began to leave their hospital roots and become independent entities that identified and managed donors, which allowed organ banks to provide organs for more than one transplant program (Howard et al., 2012). This individualization also led to the consolidation of many of the OPOs (Howard et al., 2012). Many of them were closed because they were often too small and recovered too few donors to remain economically worth keeping them open, while others were just under performing and were combined with more successful centers (Howard et al., 2012). With a more effective distribution of organs on a national scale, the question of medical decision making and the legal realities came to the fore front of the topic of organ donation.

Advanced Directives

Another key component to medical decision making is advanced directives which is a mechanism by which individuals make their medical decisions known in the event they are unable to communicate those decisions themselves. Since the 1970s advanced directives have been the primary legal tool to promote the communication of a person's end of life wishes with the goal of ensuring one's wishes are respected (Sabatino, 2010). The Euthanasia Society of America first proposed a directive in 1967 represented by Luis Kutner a human rights lawyer (Sabatino, 2010). Sabatino (2010) states that Kutner described a directive as the opportunity for a patient to protect themselves against unwanted medical treatment, as was their right provided to them based on the common and constitutional law, even when the patient is unable to make decisions due to a

medical condition. In 1976 California became the first state to adopt a living will statute, a model that provided individuals a standardized tool which to express their end of life treatment wishes and physicians statutory immunity to comply with their patients wishes in good faith (Sabatino, 2010). During the course of the next decade laws similar to this one was adopted in many states so that in 1986 41 states had adopted statutes (Sabatino, 2010).

Since the early 2000s, the Five Wishes advanced directive, which was created by the Aging with Dignity organization, has been the only advanced directive that is marketed nationally rather than on a state by state basis (Sabatino, 2010). The goal of the Five Wishes was to create an easy to use, personal, and non-legalistic instrument that met the diverse requirements across different states and districts (Sabatino, 2010).

According to Fujimori (2017) advanced directives have been cited as a way to improve patient-provider communication as it allows for patients to actively participate in informed decisions regarding their care. Conversations surrounding advanced directives often did not happen or happened very late in the process, new advanced directive efforts are aimed at promoting early and more empathetic communication, particularly as it relates to organ donation. Effective intervention focuses the decision-making process on a patient's value system while reducing the burden on caregiver by providing clarity on behalf of the patient (Fujimori, 2017).

In the creation of advanced directives, a Legal Transaction Approach was the original framework employed to convey the health wishes of patients. This framework focused on the creation and implementation of legal tools to direct healthcare decisions during a time of decisional incapacity (Sabatino, 2010). The advanced directive was

supposed to act as the highest standard of decision making for treatment, also referred to as the substituted judgement standard (Sabatino, 2010). A critique of this approach however was focused on the following seven factors; too few people use and understand legal tools, the forms are not providing guidance, patients' goals and preferences may change, when an individual names a medical proxy, the medical proxy often does not understand the wishes of the individual, healthcare providers do not always know about the existence of the directive, and finally the directive seldom affects the patients care (Sabatino, 2010). Taking these findings, it is easy to see why a new approach needed to be developed to combat these shortcomings and provide a higher level of care to patients who are in a situation where an advanced directive is needed. In response to these shortcomings, the communications approach, a more holistic approach, has become a higher standard of advanced care planning as opposed to the former legal transactional approach (Sabatino, 2010). This approach encompasses the legal paperwork, as well as discussions with both families and physicians about a patient's end of life care and how the patient's beliefs and values guided their decision (Sabatino, 2010). It has yet to be identified whether this model is in fact more effective than the previous framework employed, partly due to the fact the communications model is still being created and also due to the complex question of what the desired outcome of the model is intending to serve (Sabatino, 2010). However, the growing prominence of this approach can be witnessed through the incremental steps towards simplifying state laws, with a particular emphasis on mandatory forms and specific language that must be used. The key emphasis on the communications model has been to foster mutual participation between the physician and the patient and create relationship of shared decision making (Sabatino,

2010). This philosophy can be echoed through other communication theory specific to interpersonal and health communication such as Social Penetration Theory, Relational Dialectics Theory, and the Theory of Planned Behavior.

<i>Years</i>	<i>Timeline of Organ Transplantation History</i>
1920	Experimentation with animal transplantation begins
1936	Dr. Yu Yu Voronoy performs the first deceased donor human kidney transplantation; the patient died two days after surgery
1944	Manhattan Eye, Ear, Throat Hospital established first eye bank for cornea transplantation
1953	First living donor human kidney transplantation with a mother donating to her son, patient died three weeks later
1954	Dr. Joseph Murray performs first successful kidney transplantation with a living donor
1962	Dr. Murry performs first successful kidney transplantation with a deceased donor First successful lung transplantation
1963	Dr. Guy Alexandre performs first documented transplantation using Brain-dead patient First successful liver transplantation
1966	First successful pancreas transplantation
1967	First successful heart transplantation done by Dr. Christian Barnard Euthanasia Society of America first proposed the use of Advanced Directives Paul Teraski established first organ sharing organization in Los Angeles
1968	AD Hoc committee publishes definition of brain death Boston Interhospital Organization established organ bank
1970	Kansas is the first state to adopt a brain death statute
1972	Finland is the first nation to adopt a brain death statute
1975	American Bar Association established brain death as a legal concept
1976	California is the first state to adopt a living will statute
1977	United Network for Organ Sharing (UNOS) is established
1980	President commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research drafter the United States Uniform Determination of Death Act
1981	The United States Uniform Determination of Death Act is approved
1984	The National Organ Transplantation Act established Organ Procurement and Transplantation Network (OPTN)
1986	41 States adopted a living will statute

Table 1: Definitive timeline of major dates in the history of organ donation including medical advancements, legal advancements, and development of organ donation networks.

ORGAN DONATION SYSTEM TODAY

The United States transplant system currently is composed of a network of transplant centers, OPOs, and donor hospitals. Each donor hospital has a designated OPO and work together to promote organ donation and recovery. Organ donation and transplant policies are determined by the National Organ Procurement and Transplant Network (OPTN), which is under federal contract by UNOS. All donor hospitals must meet federal Medicare conditions and must meet accreditation requirements of the Joint Commission (Wynn & Alexander, 2010).

According to regional data collected by UNOS (2019), the northeast region, which includes Massachusetts, Maine, Rhode Island, Connecticut, and New Hampshire, there are a total of two organ procurement centers and 14 transplant centers (UNOS, 2019). Maine Medical Center is the only transplant center in the state of Maine, there are 117 patients on the UNOS list waiting for kidney transplants as of January 2019 (UNOS, 2019). Of those 117 patients, 68 have been waiting over a year for an organ to become available for transplantation. In terms of ages, 11 of these patients are under the age of 18, while 41 are over the age of 65 (UNOS, 2019). Under the laws that govern the state of Maine, an advanced directive is any written or spoken instructions that dictate the health care a patient wishes to receive should the patient become too ill to communicate their wishes (Maine Health, 2019). Advance directives in the State of Maine allow for many choices including wishes surrounding organ donation, burial and funeral services, and resuscitation (Maine Health, 2019). In Maine, citizens can create an advanced directive when they are 18 or older and the form, *Maine Health Care Advanced Directive*, can be found online through the Maine Hospital association (Maine Health,

2019). Citizens have the right to alter or cancel their directive at any time and can decide when it takes effect (Maine Health, 2019). The Uniform Anatomical Gift Act gives more legal standing to the advanced directives and other legal documents similar through the revisions made in 2006.

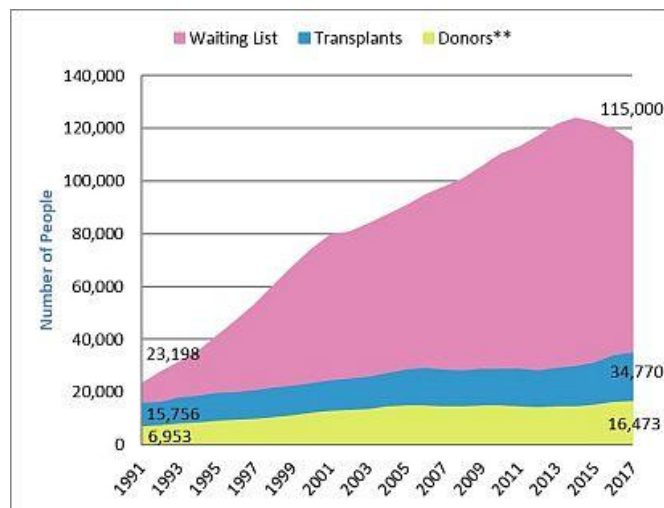


Figure 1: Graph above from the Department of Health and Human Services demonstrates the extreme shortage of organs currently being faced on a national scale, comparing the waiting list length to the number of transplants actually performed and donors both living and deceased.

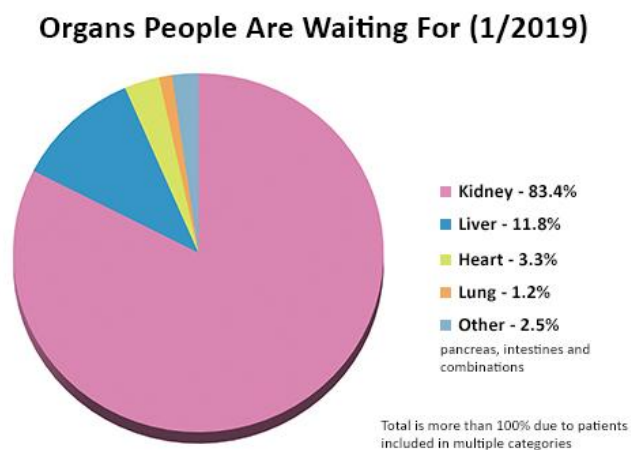


Figure 2: Graphic representation from the Department of Health and Human Services of the distribution of organs needed for those on the waiting list on a national level.

Passage of the Uniform Anatomical Gift Act

Currently, the United States operates under an opt-in system, meaning that a patient or family must explicitly state if organs are to be donated. This is unlike other countries, such as Austria, which operate under an opt-out system, where patients must explicitly decline their organs being donated (Wynn & Alexander, 2010). In 2006, there was the publication of a revision made to the Uniform Anatomical Gift Act (UAGA), which has been adopted in 44 out of 53 states, districts and territories, and allowed for persons to indicate their intention to donate previous to death by enrollment in a donor registry (Wynn & Alexander, 2010). These donor registries had existed previously, but they were often not available in real time access to the OPO staff during initial evaluation of potential donors, and the OPOs were often reluctant to proceed without consent of the legal next-of-kin (Wynn & Alexander, 2010). The passage of the UAGA allowed OPO staff to proceed with organ recovery in accordance with the donor's wishes irrespective of the wishes of others. First person authorization (FPA) is based on the principle that the decision whether or not to donate, if made by a person capable of that decision, should be respected even after death (Chon et al., 2013). In a study done of the 58 active OPOs in the United States as of 2013, 80% of OPOs have accepted FPA as the procurement policy and identified registered donor states and state laws as the most important factors in decision to pursue organ procurement or not (Chon et al., 2013). Some OPOs, however, still attempted to obtain the next-of-kin's blessing, but would still proceed with procurement if they could not be located or if there was objection. Those OPOs argued that it was reasonable to seek the next-of-kin's agreement to maintain a positive relationship with the community and as a sign of respect for the family in a time of great

emotional distress (Chon et al., 2013). The UAGA made great strides in giving patients the autonomy to be able to make the decisions but there is the need to look at the issue through the social attitudes lens to fully understand how the problem of shortage has arisen.

Current Attitudes towards Organ Donation

Throughout the United States there is large support for organ donation and there have been studies that examine the different aspects of public attitudes towards the topic. In 2012, a study was conducted titled *National Survey of Organ Donation Attitudes and Behaviors* by the U.S Department of Health and Human Services which examined on a national level the varying public attitudes concerning organ donation (Kappel, 2014). The study found that 94% of the U.S population supports organ donation, some variability however exists, between different demographics, including gender, race, and education level (Kappel, 2014). When looking at gender, 52% of females were likely to strongly support donation, while only 45% of males did so, and when looking at education levels, those who obtained a high school diploma or less indicated a 37% support rate, versus a 59% for those who had completed college (Kappel, 2014). The disconnect between high public support and the relatively low rate of organ donor registration and donation has been identified as one of the long-standing challenges in the fight to raise rates (Kappel, 2014). In addition, family refusal for consent has been another obstacle with the refusal rate between 34-38% internationally (Chon et al., 2013). Family members often have refused because of a high degree of uncomfortability when they did not directly know the wishes of the deceased but were more than six times more likely to consent when they

had one or more discussions about organ donation with the donor previously (Chon et al., 2013). Communication around the topic particularly with loved ones and family members has been identified as not only a barrier, but also an opportunity to really combat the pressing issue of the shortage of organs

COMMUNICATION AROUND ORGAN DONATION

Five factors have been identified that restrict successful transplant: willingness of people to donate, condition of the donor organs, biological matching, the condition of potential recipient, and expense and timely delivery (Kastenbaum, 2016). According to Kastenbaum (2016), the Australian government is addressing this issue by launching the initiative of “A world’s best-practice approach to organ and tissue donation for Australia,” which included establishing the DonateLife organization. A DonateLife organization has also been developed in the United States as well as regionally (DonateLife, 2019). Donate Life America was founded as a coalition in 1992, then rebranded itself in 2006 to align itself internationally with other DonateLife organizations around the world (Donatelife, 2019). As a whole these findings point to the fact that other opt-in societies such as Australia are facing similar issues to the United States which provides the opportunity for collaborative efforts between different opt-in nations. One of the major goals of this organization is to create a social norm of acceptance by normalizing the conversation about a loved one’s wishes about organ donation (Gilligan, Sanson-Fisher, Turon, 2012). According to Gilligan (2012) four key elements have been identified as foci for improving communications and overall donation rates: Creating social norms, encouraging family discussions, alleviating fears, and enabling action. Increasing general awareness and acceptance of the issue at hand on a societal level will help create the social norm of both donation as well as familial conversation about donation. Putting donation alongside other topics such as religious and political views will the topic to become a social norm which in turn can lead to acceptance and alleviate fears that surround the topic (Gilligan et al., 2012) One critical aspect of this shift towards a social

norm will be the need to ensure that people have access to accurate information about the entire processes of organ donation, this information can help to dispel myths and alleviate fears for the public (Gilligan et al., 2012). However, the major encouragement needs to focus on the discrepancy between acceptance and action, encouraging societies to make it the social norm to register (Gilligan et al., 2012). These will be instrumental in increasing organ donation rate, and inherently work together (Gilligan et al., 2012). Taking this findings into consideration, it is clear to see that combating the organ shortage is a multilayer, complex issue that looks at societal attitudes and norms as much as medical procedures and aspects.

In today's world, social networking sites are a major source of information for the younger generation and have arguably the biggest potential for public health campaigns for several major reasons: firstly they can reach a wide audience; second, messages can be delivered through existing connections; third, they have high levels of user engagement and retention; and finally, social media requires users to actively engage and generate content which could prove to be more influential than more traditional based web content (Maher et al., 2014). Communication is a two-way process, which can only be effective and potentially lead to desired outcomes if both parties have the same or at minimal similar recollections of what has been communicated (Maher et al., 2014).

Family communication is key to increasing organ donation, so it is important that social marketing campaigns therefore take family communication into account. Social marketing messages have the potential to stimulate the thought of a loved one's wishes and therefore have the potential to stimulate actual conversation. Social marketing strategies targeting this type of communication can lead to increased compliance with the

wishes of the deceased (Jones, Reis, & Andrews, 2009). Social marketing messages can stimulate families to think hypothetically about what their loved ones would want in that situation, this hypothetical in turn would stimulate (Jones et al., 2009). Jones makes clear that hypotheticals play a key role in stimulating conversation, which in turn influenced the thinking behind the coming campaign. Taking advantage of hypotheticals to ease into the conversation, to make it easier to tackle the topic is a key aspect of the following campaign. In a study conducted by Australian researchers of 23 dyads of university-student-parent dyads, researchers found effective communication campaigns should focus on increasing the knowledge of organ transplantation to be able to counter misperceptions of family members, increasing confidence with the decision made, and increasing the notion of decision importance (Jones et al., 2009). An effective campaign however, depends on the potential donors' capacity to initiate effective familial communication, so therefore a campaign should focus on promotional communication while simultaneously increasing knowledge, addressing myths and misperceptions, and increasing positive attitudes (Jones et al., 2009). According to the US Department of Health and Human Services (2019) some of the most common myths include, medical professionals giving less than adequate medical care, that rich and famous individuals receive transplants first, or that some aspects of one's life such as sexual orientation, previous medical condition, or religion prevents donation.

In another study of 50 university students examining what effect gender differences have upon familial conversations, the results indicated that women had a more positive attitude towards organ donation than men and that the topics in the conversations were likely to be different (Thompson, Robinson, & Kenny, 2003). This

study indicated that with women the familial conversations tended to include topics such as their desires to donate, the need for organs, and their reasoning for donation. More commonly, women focused their conversations towards moral, altruistic, or religious reasons, or related it to personal or family stories (Thompson et al., 2003). On the other hand, men mentioned discussing topics such as whether or not signing a donation card would affect the medical care they would receive, or they mentioned that they had not discussed donation or could not recall the conversation (Thompson et al., 2003). It is interesting to review this work to understand the role that gender plays in the targeting of the campaign and the areas highlighted by the study were ones that could be used to advantage of the campaign. Examining the role that social networking sites play directly relates back to the fundamental communication theories.

Communication Theory

Communication theories provide the basic foundation for campaigns, they can be used for a variety of different components of the campaign in order to achieve the desired outcome. In addition, they help to establish precedents for how and/or why certain health behaviors can be altered and therefore which theories should be applied to different health behaviors. The British Psychological Society (2010) conducted a research study to examine whether people's disclosure about organ donation is a reasoned and/or a social reactive pathway. The Theory of Planned Behavior (TPB) assumes that individuals have a systematic, evaluative approach towards decision making and behavioral performance. This model has been applied to a variety of different behavioral domains (Hyde & White, 2010). TPB stems from the Theory of Reasoned Action. Both theories emphasize the role

that the intention behind the modification of the behavior factors into the desired outcome (Yamasaki, Geist-Martin, & Sharf, 2017). The Theory of Reasoned Action assumes that the individual critically evaluates all the potential rewards and consequences of an action before deciding to act on the decision. Attitudes and social norms play a large role within the decision-making process for individuals (Jefferes, Carroll, Rubenking, & Amschlinger, 2009). Several factors affect intention, including an individual's feelings toward the desired behavior, the level of behavior control, self-efficacy, and the perceived role that the health behavior has within the individual social grouping. This is in comparison to the social reaction pathway of the Prototype/Willingness Model (PWM) which accounts for behaviors that have an element of risk and spontaneity and is largely dependent on situational factors (Hyde & White, 2010). Willingness is largely influenced by attitude, the subjective normal, past behavior and the actor prototype associated with the behavior (Hyde & White, 2010). Other factors however, influence decision making about communication, such as moral norm, self-identity, and people's perception of organ transplant recipients (Hyde & White, 2010). Moral norm is described as one's own personal moral values, and self-identity reflects beliefs about one's actions as something consistent with one's self concept (Hyde & White, 2010). In the end, it was concluded that people's decision to communicate was generally corresponded with the reasoned pathway such as the TPB, but that the discussion itself involved more reactive elements as was discussed in the PWM. When applying the PWM to organ donation, a suggestion made was "people should be encouraged to take advantage of any unexpected opportunities for communication which may overcome barriers to communicating donation wished" (Hyde & White, 2010). Since the emergence of both moral norm and

self-identity on both TPB and PWM, promoting communication of the donor's decision as "the right thing to do" and encouraging direct statements about the decision confirms the donor identity through behavior (Hyde & White, 2010). When thinking about these theories in terms of the campaign for increasing the familial conversation about donation, the campaign should emphasize the idea to seize the opportunity to have the conversation when a donor has come to the decision through a systematic evaluation. The emphasis of these two theories on the campaign aimed at the processes recommended by the campaign. First, the decision about what the donor wishes after death must be made so as to solidify their position. This is where the TBP comes into the campaign, supporting the audience in deciding through a systematic process. Second, it encourages the audience to seize the opportunity when they feel secure in having the conversation, that it doesn't necessarily need to be a formal conversation and thoroughly planned. There are so many small opportunities through things such as social media stories or pop culture that connect to the topic that allow for a gateway into the conversation. These two specific theories guided the plan developed for this project.

Other theories were heavily considered in the campaign plan, including the Social Penetration Theory and Relational Dialectics. Social Penetration Theory was developed by Irwin Altman and Dalmas Taylor when they proposed the social penetration process (Altman, Talyor & Sorrentino, 1969). This is the process by which deep intimacy is developed with another person through mutual self-disclosure and other forms of vulnerability. Taylor and Altman compared the personality structure to an onion, where different layers are different levels of beliefs and feelings about oneself, others around them, and the world. The deeper the layer, the more the topics are vulnerable, protected,

and closer to one's self-image (Griffin, Ledbetter, & Sparks, 2019). Theorists identified the main route to deep social penetration is self-disclosure, which is the voluntary sharing of different aspects of one's personal history, preferences, attitudes, and other such aspects to one's self with another person (Griffin et al., 2019). Two key aspects of the framework of self-disclosure are depth and breadth of social penetration. Depth refers to the degree of disclosure in a specific area of an individual's life (Griffin et al., 2019). Peripheral items are generally exchanged sooner into the relationships and more frequently than private information. Self-disclosure is generally reciprocal, particularly earlier into the relationship. Penetration is rapid at the start, but eventually it slows down as inner and more protected layers are reached (Griffin et al., 2019). Breadth of penetration refers to the different range of areas that one discloses. People regulate the closeness of a relationship based on the potential rewards or costs they face during an interaction (Griffin et al., 2019). Social exchange is the relationship behavior and status regulated by both parties' evaluation of perceived rewards and costs of each interaction with each other (Griffin et al., 2019). This plays an important role because a topic as delicate and as serious as organ donation will most likely be a deeper and therefore more protected layer than more surface level information such as trivial favorites. So, the conversations when facilitated will most likely need to be held by someone who the discloser has developed a close relationship with. The conversation will also need to come at a point where the discloser believes that the cost of disclosure is lower than the potential reward of a person respecting their wishes if the time ever comes that the decision needs to be made. Understanding that this is a sensitive and deep layer topic angled the campaign to respect this when creating media. Within the practical application

of the campaign created, this theory was applied again at the messages that are created, specifically at who the audience would be communicating with about the decision they had made. The key aspect to the campaign is centered around familial conversations, in order for these to occur in a healthy and productive manner the level of intimacy between those having the conversation must be deep through self-disclosures.

The second theory that is key to the developed campaign is Relational Dialectics Theory (Baxter, 1988; Montgomery, 1988), which examines the dynamic and unceasing struggle between discourses about interpersonal communication. The theory view relationships as a ceaseless productive interplay of opposing tendencies, however this is not to imply conflict. Three common dialectical tensions shape the relationships: integration/separation, stability/change, and expression/non-expression (Griffin et al., 2019). These discursive struggles that occur internally within the relationship and externally between the couple and the wider community, so it is important to consider both when analyzing them (Griffin et al., 2019). Integration/separation refers to the discursive struggles regarding independence versus interdependency. Stability/change refers to the discursive struggles about routine versus spontaneity. Finally, expression/non-expression refers to the discursive struggle between transparency versus secrecy (Griffin et al., 2019). The applications identified have been both familial communication and health communication. When looking in terms of the following this theory will allow the media create to navigate the internal and external tensions of the relationships the campaign identifies in attempt to minimize them. The campaign created took tensions into consideration in order to specifically navigate them. For example, when a college student begins the conversation with their parent or guardian, they are

seeking to navigate the internal tension of Integration/Separation, the connection to their family but also the autonomy to make their own decisions. In addition, relational dialectics was important for the delivery of the campaign, those on the actual campuses to understand the external tensions because they would be the wider community. The understanding that these tensions translate differently, both externally and internally, will allow for different people to approach the topic in different ways to navigate the tension.

Communication in Campaigns

When considering then communication through a health campaign, it is important that the intended product, in this case organ donation, is seen as something positive, that can have benefits for the donor, the family, and the recipient. These benefits include potentially psychological benefits that the family has fulfilled and honored the wishes of their loved one (Jones et al., 2009). Another aspect that campaign should highlight the urgency and importance of preemptive communication because it could increase the likelihood that communication will occur and add more specificity and direction to the conversations (Jones et al., 2009). The more specific a conversation is particularly in the areas of what the person would want or not want to be donated in terms of specific organs, as well as the specific conditions of donation can increase a family's confidence in the decision making (Jones et al., 2009). In an editorial published in *The American Journal of Medicine* (2014), authors pointed out that having more public recognition of surviving families could help to stimulate conversation about important problems (Woodfine & Redelmeier, 2014). Organ donation is not entirely a private decision. Families should be included, because informed families can then advocate for the patients

if they are unable to for themselves (Woodfine & Redelmeier, 2014). This public recognition could also help to shift the public norms to allow for others to then have the conversation with their loved ones (Woodfine & Redelmeier, 2009). A potential drawback, however, infringing upon a family's grief during a vulnerable time through the release of private information is important to note (Woodfine & Redelmeier, 2014). The editorial also made mention that families generally never get mentioned because of the certain reluctance in society to discuss death, there are some people however, may be able to better connect to the grieving families who choose donations over the more traditional campaign focus of recipient patients (Woodfine & Redelmeier, 2014). The authors conclude with "American families remain unaware of the role they must play in the deceased organ donation decision. Public honors might help to venerate an otherwise taboo medical topic" (Woodfine & Redelmeier, 2014). Having the central idea of family conversation as the focus of the campaign would therefore help to educate the family on their role as well as benefit the patient so his or her wishes are heard.

GEORGE WASHINGTON UNIVERSITY MEDIA/COMMUNICATION PLAN

The campaign plan was developed using a template developed by George Washington Cancer Institute for a Media/Communication Plan and is also largely influenced by other literature on campaign design. It is important to note the differences between a communication and a media plan, and the decision process for creating a media plan over a communication plan. A media plan is a subset of a communication plan, where the focus is on informing and engagement through different media specifically. The campaign includes several different types of media including paid, earned, and owned media (National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control (DCPC), Comprehensive Cancer Control Branch, Center for Disease Control and Prevention, 2014). A communication plan has a wider array of strategies than a media plan, each aimed more towards different goals that are subsets of an overarching goal. The decision to focus on developing a media plan was due to the audience, being aimed a younger generation where there is a higher level of exposure to different types of media. A media plan also allows for more application of similar strategies on different media rather than entirely different tactics and strategies being developed. A media plan also allows for more cohesion across the plan, specifically when working in relatively small communities rather than on something as large as a national scale (National Center for Chronic Disease Prevention and Health Promotion et al., 2014).

The major sections of the campaign plan include a justification, a SWOT analysis, objectives summary, audience justification, a tactical timeline and finally an evaluation plan to serve as a proposal for the campaign. There is no single plan that will work for all

health problems that different adaptations must be made to fit the campaign and its objectives.

SWOT Analysis

The first step in the campaign development was an environmental scan, in this case a Strengths, Weakness, Opportunities, and Threats (SWOT) analysis was used. A SWOT analysis allows for greater understanding of the problem, which allows for more success in addressing the issue. It is important to identify these different aspects to address them within the campaign, allowing for the creation of a well-rounded and comprehensive plan. For this specific campaign it was identified that opportunities include the extensive amount of research and statistical information that is available through reputable sources, as well as emotional appeals of the various parties that the topic touches such as the donors, recipients and families. The various weaknesses that were identified included the various myths that face the topic such as misconceptions about brain death or lack of understanding the decision. The main opportunities that were identified focused on the support that the American people have for the topic, the need for organs defies racial, socioeconomic, gender, age lines. The largest threat to this is the cultural attitudes towards death, it is not a common place topic and with the inherent connection to death that organ donation has, this cultural attitude threatens to shut the campaign down. In addition, the system of opt-in versus opt-out is a threat to any campaign that attempts to address the issue.

<p style="text-align: center;"><u>STRENGTHS</u></p> <ul style="list-style-type: none"> • Significant amount of research done previously on the topic • The statistical representation to the need in society • Emotional appeals of donors, recipients, and families on either side 	<p style="text-align: center;"><u>WEAKNESSES</u></p> <ul style="list-style-type: none"> • Misconceptions about brain death • Lack of communication between potential donors and decision makers • Lack of understanding of process of becoming a donor, and donation • Families experiencing time pressure to decide about donation • Disagreement between potential donor and religious affiliations
<p style="text-align: center;"><u>OPPORTUNITIES</u></p> <ul style="list-style-type: none"> • Documented need for organs that defies racial, gender, age and many other demographic lines • Increased accessible educational materials that are easy to understand • Medical advances making donation safer and more effective than previous treatment methods since the conception 	<p style="text-align: center;"><u>THREATS</u></p> <ul style="list-style-type: none"> • Societal attitudes towards death and dying • Societal communication habits and attitudes between next of kin and young adults • Misconceptions about registration process and donation process as a whole • The U.S being an opt-in rather than an opt-out

Objectives Summary

The next step in the process is an objectives summary, based off of the environmental scan, to decide what exactly the objectives of the campaign. The objectives are broken down into communication, behavioral, and health objectives. The determination of the exact outcome goal is based off the objectives and the environmental scan (Yamasaki et al., 2017). These objectives were result orientated and followed the S.M.A.R.T model (Specific, Measurable, Attainable, Relevant, and Time-bound). Four out of the five parts of the goal were addressed in the plan, with the exception of the time-bound aspect. There was no effective way to quantify it due to the nature of the organ donation topic.

Communication Objectives (COs)

To increase education and communication about Organ Donation for college age young adults so they have a better understanding of what the decision actually is.

To increase a formal sit-down conversation between young adults and their medical decision makers, parents, spouses, etc, about their organ donation decisions.

To create communication that is clear and open about the decision that is made, so that there is little questioning of how or why the young adult came to the conclusion that he or she did.

Behavioral Objectives (BOs)

To increase more young adults having a conversation about their decision regarding organ donation with those who would in theory be making the decision if they were to become unable to make the decision.

To increase the family's knowledge of the role they could potentially play in their loved one's medical decision.

To increase the willingness of the potential medical decision makers to sit down and listen to the young adult about his or her decision and the reasoning.

Health Objectives (HOs)

To increase the number of young adults that have made an informed decision whether or not to be organ donors and have expressed that decision to medical next of kin.

To increase healthy communication about difficult or not socially acceptable health topics

Audience

The next aspect considered was audience identification and justification. An audience analysis is conducted within the environmental scan. This is typically determined from direct communication and research through focus groups, surveys, and other tactics, as well as existing data on the target populations (Yamasaki et al., 2017). There are two layers of audiences, and both must be addressed in the justification. The first is the primary audience, who are the intended and direct audience, while the secondary audience are those who may be impacted by the campaign either indirectly or directly through the primary audience (National Center for Chronic Disease Prevention and Health Promotion et al., 2014). Understanding the audiences allows effective crafting of messages in order to be able to reach the goals of the campaign. When crafting these messages, the audience also comes into play, because messages created must consider culture and be culturally aware. The audience that was chosen for this particular campaign was These messages also must resonate with the audience and resonate well enough to counter resistance (Yamasaki et al., 2017).

The target audience would be traditional college aged students ages 18-23 studying at universities. The secondary audiences would therefore be others on the campus who don't fit within those age ranges, such as staff, faculty, and nontraditional students. Another secondary audience would be parents or others, such as spouses or siblings, who college students would then be having the conversations with eventually. The reasoning behind the selection is that the demographic has an interesting attitude towards donation and willingness to donate. A study identified family communication as key to increasing organ donation rates. This study also identified indicators that as

parents transmit their attitudes onto their children, there should be an awareness of the role they play within this process (Jones et al, 2012). The study concludes, “Targeting social marketing campaigns at parents (and perhaps concurrently at their adult children) would be an important step” (Jones et al, 2012). University aged students are on their own for the first time, and now they are legally adults who have made many decisions that actually become theirs. Despite being as young as 16 when able to indicate on a license whether or not to become organ donors, it seemed that at 18 and those young adult years it was the first time to be able to fully process what exactly that means. The choice for the first time is really in the young adult’s hands, because until then it has technically been the parent’s or legal guardian’s legal decision. According to a systematic review published in the *Journal of Medical Internet Research*, online social networks have had an enormous growth in popularity as a platform to deliver mass-reach health campaigns, because they can reach a wider audience, messages can be delivered between existing contacts, and they are high in user engagement and retention (Maher et al, 2014).

Plan Tactics and Timeline

Synthesizing all of this information into a tactical timeline allows for an understanding of the implementation of tactics that will be used to achieve the previously identified goals and objectives of the campaign. In order to be effective, these need to be well thought out and comprehensive, rather than just vague ideas (National Center for Chronic Disease Prevention and Health Promotion et al., 2014). At this stage, there will be the identification of the media outlets for the messages. For this particular campaign plan, media that is heavily used by student will be the best approach specifically looking at social media such as Instagram and Facebook, as well as campus specific media such as campus newspapers. Using a multimedia approach can increase exposure to the messages for a greater impact. It is important that the media chosen fits with the demographics and media consumption with the chosen audiences, as well as work within the other constraints such as the budget, time frame, and geographic area (Yamasaki et al., 2017). There will also need to understand that there may be adjustments later in the process as other things shift, so it needs to have a certain degree of flexibility (National Center for Chronic Disease Prevention and Health Promotion et al., 2014). One adjustment that needs to be heavily considered is the differences between campuses; some have different student life emphases in different areas. For example University of Maine has a large Greek Life presence that can be capitalized on, whilst this may not be true for all universities. The recognition of the differences allows for the campaign to be better molded to that specific community which could lead to a higher degree of success.

<p>COMMUNICATION OBJECTIVE 1: To increase a formal sit-down conversation between young adults and their medical decision makers, parents, spouses, etc, about their organ donation decision.</p>
<p>Related Health Objective(s): To increase the number of young adults who have made an informed decision whether or not to be organ donors and have expressed that decision to their medical next of kin.</p> <p>Related Behavioral Objective(s): To increase more young adults having a conversation about their decision regarding organ donation with those who would in theory be making the decision if they were to become unable to make the decision.</p>
<p>Target Audience(s): Primary audience: College Age (18-23) young adults; Secondary Audience: Next of kin of who will be making formal organ donation decision, non-traditional college students that will be reached by campaign</p>
<p>Key Message(s): Due to the fact that we live in an opt-in society, it is important to make an educated decision, whether or not to be an organ donor, that is discussed openly and honestly with loved ones, so that if the time comes they can make the decision that you would have wanted.</p>

	Tactics/ Channels/ Activities	Budget and Resources	Staff responsible/ Stakeholders involved	Output/Outcome measures
Months 1-3 Planning	<input type="checkbox"/> Determine best methods and platforms that can be used <input type="checkbox"/> Determine the criteria that will be used to decide which universities should be used, such as region, size, type	<p>Comparative literature, statistical information, minimal financial resources</p>	<p>Research, Marketers</p>	<input type="checkbox"/> A comprehensive list of what will be happening, where, when and why. <input type="checkbox"/> A direct and detailed

Months 4-6 Early Implementation	<input type="checkbox"/> Determine which universities will be used in the different stages of the campaign with demographic information collected and reasoning written out <input type="checkbox"/> Determine the registration process in each state that the host universities are in <input type="checkbox"/> Determine current state of Organ Donation in each state that the host universities are in <input type="checkbox"/> Application for Grants and funding			<p>timeline of what will be occurring.</p>
	<input type="checkbox"/> Tabling at universities with information about both national and local levels of Organ Donation, really focused on easy to understand language <input type="checkbox"/> Using Public universities that are in the Northeast that are of student populations between 5,000-15,000 students <input type="checkbox"/> Materials on how to have the conversation with parents and or loved ones about the decision that is made, including information on why the	<input type="checkbox"/> Marketing materials <input type="checkbox"/> Tabling Materials <input type="checkbox"/> Formal Presentation developed <input type="checkbox"/> Budget \$10,000	<input type="checkbox"/> On-campus coordinators ages 23-30 that would be working directly on campuses <input type="checkbox"/> Student Life campus staff (not to be on the payroll but as a key stakeholder)	<input type="checkbox"/> Connections with the campuses <input type="checkbox"/> Starting a conversation with students about why this is an important conversation to have

Months 7-9 Wide Spread Implementation	conversation is so difficult to have <input type="checkbox"/> Hosting on campus information sessions and events geared at guest speaking at different on campus organizations such as with sports teams, Greek life, honors societies, clubs, etc. <input type="checkbox"/> Connecting with on campus newspapers and news outlet to get out the message in Press Releases <input type="checkbox"/> Connecting through social media and getting a following going			
	<input type="checkbox"/> The same tactics as stated above but really on a larger scale with more universities that stretch across larger demographical barriers	<input type="checkbox"/> Larger budget needed \$30,000	<input type="checkbox"/> On-campus coordinators ages 23-30 who would be working directly on campuses <input type="checkbox"/> Student Life campus staff (not to be on the payroll but as a key stakeholder)	<input type="checkbox"/> Creating a larger connection with more diverse campuses <input type="checkbox"/> Creating a following for the importance of the conversation

<p>Months 10-12</p> <p>Evaluation</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Surveying campuses to find out how many students had actually had the conversation and what the result was <input type="checkbox"/> Including demographic information so as to be able to compare across the region to see if an adjustment should be made for different sized universities or other contributing factors <input type="checkbox"/> Outgoing interviews with each staff members of their different visits for providing qualitative data as to their experiences and how it compares against data collected from students 	<ul style="list-style-type: none"> <input type="checkbox"/> Online Surveying developed compatible with different universities system, sent out through Student Life Offices 	<ul style="list-style-type: none"> <input type="checkbox"/> Student Life offices <input type="checkbox"/> Data analyst 	<ul style="list-style-type: none"> <input type="checkbox"/> Understanding the overall effectiveness of the campaign <input type="checkbox"/> Understanding the effectiveness at the different universities <input type="checkbox"/> Seeing what mistakes were made and how can they be improved upon
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Evaluation Plan

The final part of the campaign plan is the evaluation in order to measure the level of effectiveness of the campaign. It is noted that effective campaigns are built off scientific and communication theories that have evaluative techniques built into the plan (Yamasaki et al., 2017). This will determine if the campaign succeeded in meeting its goals, if it did how effectively and if it didn't try to figure out why it didn't.

1. Engage stakeholders

Those involved in promoting organ donation, such as the United Network of Organ Sharing or the Department of Health and Human Services, would be key stakeholders because they would be able to use this information to better promote registration. It would also benefit those who will be in the position of assisting with donation, because the more conversations people are having with those who might be making the decision, the easier that process will be and hopefully the more donations will be made. These stakeholders would then be responsible for the effective application of the responses.

2. Describe the program

This is a campaign aimed at engaging traditional college students at beginning the conversation with families and loved ones about organ donation. This was identified as one of the main obstacles for successful donation because families feel uncomfortable giving permission when they do not directly know the wishes of their deceased loved one. Much of the communication strategies have been aimed at interpersonal communication between the staff and the collegian on both education and how to begin

communicating properly about the wishes. The ultimate goal is to normalize the conversation about organ donation, breaking through the social barriers and social stigmas around death and dying. One of the major inspirations for this program has been the DonateLife organization in Australia as a part of launching, “A world’s best-practice approach to organ and tissue donation for Australia” (Gilligan et al 2012). A huge part of this idea has been encouraging action, and while Australia has been focused on encouraging action through registration, the created campaign’s focus remains on encouraging action through communication.

3. Focus the evaluation design

The purpose behind evaluation would be to see how many people are willing to make the decision and stick with the decision enough to express to loved ones what they want. The goal would be to learn how approaching a health behavior of this magnitude through communication change the outcome of the health behavior, rather than approaching in through a healthcare standpoint. In addition, does approaching it through a communication standpoint change the societal response as to the social stigma. In essence does communication have the ability to break through social stigma and societal norms?

The overall design will be reflected back in a survey administered through the student life centers, or whatever they may be titled, on whether or not action was taken and what was the response. In the initial conversations, staff will be making students aware that an anonymous and optional though highly encouraged survey will follow. Health topics can be deeply personal, and it would be counterproductive to force students to discuss these issues if it would have an adverse effect. A second part of evaluation would be narratives about experiences through the staff as a qualitative evaluation of their experiences as the

staff. What types of conversations would they be having? How did they feel the different conversations went, compared to each other? Sitting down in an interview with analysts and sharing their experiences will be important insight from differing perspectives.

4. Gather credible evidence

Indicators of success would be students taking the time to have conversations with their loved ones and that those conversations are perceived by the students to be positively received. The survey would be set up with the Likert-type scale questions with open-ended sections to address the why. This provides both quantitative and qualitative data for analysts to be able to use. The surveys will be available to all those who either attended an information session or stopped by the tabling efforts as sent out through the student life centers. In addition to the students, there will be an interview portion from staff to get a secondary perspective which will be aimed, the response of the students to the program. This will only be qualitative data and may or may not be used in the formal report findings.

5. Justify conclusions

Data will be analyzed through statistical significance, looking for data patterns among the quantitative portions of the surveying. The qualitative methods will be observed and synthesized using key words and phrases. These key words and phrases will be identified through campaign material such as a slogan. Data will also be divided into different demographic groups, such as gender, race, familial status, etc., as to be able to compare data across these groups, looking for potentially statistically significant patterns.

6. Ensure use and share lessons learned

The communication of findings will be written in a paper, including the justification as to why a campaign was needed, the explanation of the campaigns working, similar to the template, and finally the results including an interpretation of the data based on previous research on the subjected evaluated in the justification.

CONCLUSION

Familial communication is one approach to solving the massive shortage of organs in the United States. The history of organ donation and the legal institutions that aide it provides important insight into how the system was created and therefore how to help solve the shortage. Examining the current situation allowed for the examination of weakness of the opt-in system The United States has adopted. All of this information then allowed for a campaign to be created based on fundamental communication theories that specifically targeted the shortage from the angle of familial conversation.

This campaign sought to help to stimulate conversation between traditional college aged students with their next-of-kin, in the hope that if there was ever a situation where the decision needed to be made that the family would be equipped with all the knowledge they need to make the decision that aligned most accurately with the decision of the patient. Through application of the Prototype Willingness Model, a major emphasis was placed on taking advantage of spontaneous conversations that stem from real world stimuli such as pop culture and other media. Understanding that not every college aged student had come to a decision, this campaign also sought to apply the Theory of Planned Behavior to give students the information they needed to systematically come to a decision that best suited them and their lives.

While this campaign was focused more towards the geographical area of Northeastern universities, the hope would be extending it to a national campaign with adjustments being made for the different cultural and geographical areas. Organ donation has evolved in many ways since the beginning experimentation of the 1920s, but one fact remains the same, there is a massive shortage of organs that could be used to help save

tens of thousands of lives, and this campaign seeks to minimize that shortage through familial communication.

REFERENCES

- Advance Directive. (2019). Retrieved from <https://mainehealth.org/services/hospital-medicine/advance-directive>
- Barker, C. F., & Markmann, J. F. (2013). Historical overview of transplantation. *Cold Spring Harbor perspectives in medicine*, 3(4), a014977. doi:10.1101/cshperspect.a014977
- Baxter, L.A. (1988). A dialectical perspective of communication strategies in relationship development. In S. Duck (Ed.) *Handbook of personal relationships* (pp.257-273). New York: Wiley
- Chon, W. J., Josephson, M. A., Gordon, E. J., Becker, Y. T., Witkowski, P., Arwindekar, D. J., . . . Ross, L. F. (2013). When the living and the deceased cannot agree on organ donation: A survey of US Organ Procurement Organizations (OPOs). *American Journal of Transplantation*, 14(1), 172-177. doi:10.1111/ajt.12519
- Department of Health and Human Services. Statistics & Stories. (2019). Retrieved from <https://www.organdonor.gov/statistics-stories.html>.
- Donate Life America. About Us. (2019). Retrieved from <https://www.donatelife.net/mission-vision/>
- Fujimori, M. (2017). ES 06.01 Advanced directives — are they useful? *Journal of Thoracic Oncology*, 12(11), S1622-S1623. doi:10.1016/j.jtho.2017.09.126
- Gilligan, C., Sanson-Fisher, R. W., & Turon, H. (2012). The organ donation conundrum. *Progress in Transplantation*, 22(3), 312-316. doi:10.7182/pit2012216
- Griffin, E. A., Ledbetter, A., & Sparks, G. G. (2019). *A first look at communication theory*. New York, NY: McGraw-Hill Education.
- Hansen, S. L., Eisner, M. I., Pfaller, L., & Schicktanz, S. (2017). “Are You In or Are You Out?!” Moral appeals to the public in organ donation poster campaigns: A multimodal and ethical analysis. *Health Communication*, 33(8), 1020-1034. doi:10.1080/10410236.2017.1331187
- Howard, R. J., Cornell, D. L., & Cochran, L. (2012). History of deceased organ donation, transplantation, and organ procurement organizations. *Progress in Transplantation*, 22(1), 6-17. doi:10.7182/pit2012157
- Hyde, M. K., & White, K. M. (2010). Are organ donation communication decisions reasoned or reactive? A test of the utility of an augmented theory of planned behaviour with the prototype/willingness model. *British Journal of Health Psychology*, 15(2), 435-452. doi:10.1348/135910709x468232

- Jones, S. C., Reis, S. L., & Andrews, K. L. (2009). Communication about organ donation intentions: Formative research for a social marketing program targeting families. *Social Marketing Quarterly*, 15(2), 63-73. doi:10.1080/15245000902894040
- Jonsen, A. R., (2012). The ethics of organ transplantation: A brief history. *AMA Journal of Ethics*. Retrieved May 17, 2019 from <https://journalofethics.ama-ass.org/artical/ethics-organ-transplantaiton-brief-history/2012-03>
- Kappel, D. F. (2015). Organ donation in the United States—2014. *Journal of Legal Medicine*, 36(1), 7-16. doi:10.1080/01947648.2015.1047299
- Kastenbaum, R. J. (2016). *Death, Society and the Human Experience*(11th ed.). New York, NY: Routledge.
- Keller, K. A. (2003). The bed of life: A discussion of organ donation, its legal and scientific history, and a recommended "opt-out" solution to organ scarcity. *Stetson Law Review*, 32(4), 855.
- Maher, C. A., Lewis, L. K., Ferrar, K., Marshall, S., Bourdeaudhuij, I. D., & Vandelanotte, C. (2014). Are health behavior change interventions that use online social networks effective? A systematic review. *Journal of Medical Internet Research*, 16(2). doi:10.2196/jmir.2952
- McCarthy, M. (2015). US initiatives to boost organ donation have had little effect, study finds. *Bmj*, 350(Jun05 13). doi:10.1136/bmj.h3103
- Montgomery, Barbara. (1988). A dialectical analysis of the tensions, functions and strategic challenges of communication in young adult friendships, *Communication Yearbook 12*, Ed. James A. Anderson, Newbury, CA Sage, 157-189.
- National Center for Disease Control and Health Promotion; Division of Cancer Prevention and Control; Comprehensive Cancer Control Branch; Centers for Disease Control and Prevention. (2014). *How to create and implement an effective media plan*[Brochure]. Author. Retrieved May 18, 2019, from [https://smhs.gwu.edu/cancercontroltap/sites/cancercontroltap/files/Media Plan Guidance 07 08 2014.pdf](https://smhs.gwu.edu/cancercontroltap/sites/cancercontroltap/files/Media%20Plan%20Guidance%2007%2008%202014.pdf)
- OPO History. (2019). Retrieved from <http://www.aopo.org/about-opos/history-of-opos/>
- Organ Donation Statistics. (2019). Retrieved from <https://www.organdonor.gov/statistics-stories/statistics.html#expandcollapse>
- Sabatino C. P. (2010). The evolution of health care advance planning law and policy. *The Milbank quarterly*, 88(2), 211–239. doi:10.1111/j.1468-0009.2010.00596.x

- Taylor, D. A., Altman, I., & Sorrentino, R. (1969). Interpersonal exchange as a function of rewards and costs and situational factors: Expectancy confirmation-disconfirmation. *Journal of Experimental Social Psychology*, 5(3), 324-339.
doi:10.1016/0022-1031(69)90057-2
- Thompson, T. L., Robinson, J. D., & Kenny, R. W. (2003). Gender differences in family communication about organ donation. *Sex Roles*, 49(11/12), 587-596.
doi:10.1023/b:sers.00000003129.25173.ad
- UNOS Data and Transplant Statistics | Organ donation data. (2019). Retrieved from <https://unos.org/data/>
- Woodfine, J. D., & Redelmeier, D. A. (2014). New thinking about honor and deceased organ donation. *The American Journal of Medicine*, 127(9), 802-803.
doi:10.1016/j.amjmed.2014.05.021
- Wynn, J. J., & Alexander, C. E. (2011). Increasing organ donation and transplantation: The U.S. experience over the past decade. *Transplant International*, 24(4), 324-332.
doi:10.1111/j.1432-2277.2010.01201.x
- Yamasaki, J., Geist-Martin, P., & Sharf, B. F. (2017). *Storied health and illness: Communicating personal, cultural, & political complexities*. Long Grove, IL: Waveland Press.

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Outside of academics she is a proud sister of Delta Delta Delta and has helped in Spring 2017 to re-establish the Alpha Kappa chapter at the University of Maine. There she has held the positions of Vice-President of Community Relations and the Director of Public Relations and Marketing. Tri Delta has also given her the opportunity to become involved with St. Jude Children's Research Hospital as their national philanthropic Partner. Vibert has run two half-marathons as a St. Jude Hero, and in Summer 2018, she visited the campus in Memphis as part of the Tri Delta St. Jude Celebration conference. In Fall 2017, she was inducted into the Greek Honor Society Order of Omega and in Spring 2018, she was inducted into the Communications Honor Society Lambda Pi Eta, where she also has held the position of Vice-President for her senior year of college. In Spring 2019, she was inducted into Phi Beta Kappa honor society.